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ABSTRACT

A conference sponsored by the World Health Organization (WHO) Regional Office for Europe addressed the provision of self-care health education in Europe. The 15 participants came from a variety of nations and backgrounds. Their roles ranged from WHO officials to community organizers, health practitioners, and health educators. The WHO Regional Office staff provided introductory statements on the proposed WHO program for promoting self care skills in Europe. Discussions followed on: (1) an international perspective on self-help and mutual aid; (2) consumer-centered health care; (3) the Giugliano action research project; (4) the role of health education in facilitating self help; (5) a general practitioner's view of education for self care; (6) self-help in the USSR; (7) the Feminist Women's Health Center in West Berlin; (8) research on the role of the family in self care for chronic illness; and (9) the key role of personal and local self help in a new development path. The feasibility of establishing a European clearinghouse on self help and self care was explored. The group came to several conclusions about the role of the WHO Regional Office in promoting self care in Europe. A list of the participants is appended. (FG)

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SELF-HELP AND HEALTH

Report on a WHO Consultation

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CONTENTS

		Page
1.	Purpose of the Consultation	1
2.	Background and methodology	1
3.	Scope of self-help and health	3
	3.1 Self-help and mutual aid: an international perspective	3
	3.2 The concept of consumer-centred health care	5
	3.3 Participation in health care: the Giugliano action research project in Naples	6
	3.4 Role of self-help for health education: role of health education for self-help	7
	3.5 Education for self-care: a general practitioner's view	9
	3.6 Self-help in the USSR	10
	3.7 The Feminist Women's Health Centre in Berlin (West)	11
	3.8 Research issues in self-care: role of the family with special regard to chronic illness	12
	3.9 Key role of personal and local self-help in a new development path	13
4.	Feasibility of a European clearing-house on self-help and health	15
5.	Conclusions and recommendations	17
Annex	List of participants	19

1. Purpose of the Consultation

The WHO Regional Office for Europe is at a turning point in its interest and action in health education. The medium-term programme on health education for the remaining part of WHO's Sixth General Programme of Work reflects a new emphasis on health promotion, disease prevention and supportive health education (self-care/self-help). In order to develop each of these programme thrusts, the Regional Office plans to inform its strategies through consultation and active participation of citizens and relevant government and nongovernmental organizations. The Consultation was called with special reference to supportive health education, although it is recognized that there is a necessary overlap of all three programme aspects. Specifically, the group was asked to address three topics:

(1) the scope of mutual aid, self-help and self-care for the provision of health care in the European Region;

(2) the outcomes expected from the Regional Office programmes on mutual aid, self-help and self-care - especially with regard to the establishment of a European clearing-house on self-help and health;

(3) recommendations on the self-help/self-care policy of the Regional Office with special regard to the regional strategy for attaining health for all by the year 2000.

2. Background and methodology

The rather bland list of expected topics for the Consultation may mask the innovations in its planning and execution. As recognized by the Regional Office, the new directions for health education are based on an appreciation that health is a political idea. Health education historically has been preoccupied with the individual as the cause of disease, with scant attention to environmental, social, economic and political sources of stress. Thus, interest in facilitating or promoting group action was only marginal. Health education also has been professionally dominated, and this has led to approaches that (1) define the health problems and priorities for the community, and (2) define (limit) the range of acceptable solutions to those involving professional (usually "scientific") help. There was little awareness of lay people themselves as effective resources in health care. Similarly, health education as an extension of the professional health care establishment did not recognize the many social institutions already existing (such as the church, unions, voluntary women's health groups, friendship networks) that provide unique curing and supportive health services.

The Regional Office's approach to health education, as set out in its medium-term programme, was presented to the meeting in a discussion document. The intent was to stimulate critique, clarification and suggestions for revision, with nothing held sacred or unchangeable. Indeed, it is the intention of the Regional Office to engage in a decision-making process derived from the values, concerns and priorities of its constituents - a process of continuously being informed. In this sense the means of programme development are consistent with a major goal of making the Regional Office's health education resources both responsive and available in acceptable and useful ways.

Naturally, such an open stance means that it is necessary to seek the contribution of a variety of new voices - those of people working to strengthen the competence of individuals in health care; those participating in mutual-aid groups (with roles ranging from support to political action); those who help organize communities for health improvement; and those whose work contributes to health care through social institutions that stand between the individual and the powerful structures of government and the professional health monopolies. Those invited to participate in the meeting represenced a cross-section of such persons (see Annex). Many of these new voices constituted social, nonprofessional resources in health never (or rarely) consulted by professional health bodies, including WHO. Their expectations in being invited to participate in a consultation cannot be assumed to be the same as those of the WHO host. And in a similar way, the WHO convenors could not (and did not) expect to see the Consultation proceed passively as an orderly exercise, being tied to predetermined definitions, limited to a tight agenda, and bound to come up with recommendations. The established WHO modus operandi of research, recommendations and reports was simply not applied to this Consultation. Its style was definitely more one of dialogue, determination, and doing.

Reference to the regional strategy for attaining health for all by the year 2000 helped the participants place their contributions in the context of the WHO mandate and at the same time it helped to sharpen understanding of the need for flexibility in carrying out that mandate. Dr J. Asvall highlighted implications of the strategy in promoting both personal and social competence

of lay people for health care. In what ways, he asked, can self-help activities in health enhance the benefits of both lay and professional resources? And in what ways can the Regional Office assist in this process? Finally, he called for attention to these questions in a way which is relevant to the full spectrum of cultural and economic situations, and particularly poverty.

Given that the meeting was for several of the participants their first exposure to WHO, questions were put to Regional Office staff regarding WHO's structures and functions generally, and specific information was sought regarding the realities of what WHO can do. Dr M. Wagner responded with an overall review of the Organization. He emphasized WHO's "servant" role in relation to Member States, who can recommend and veto programmes. Although WHO works officially with the ministries of health, there are possibilities for working with individuals or groups within Member States. WHO and its regional offices may invite anyone to attend meetings as non-official representatives. For example, as it becomes known that the Regional Office for Europe is seeking input on self-care and self-help, many new nongovernmental contacts will be made. The question of how far the Regional Office can go in support of and collaboration with nongovernmental resources in programme deelopment is an open question, but they are now asking for collaboration in research and this may have effects beyond the research activity itself.

In further response to questions concerning the effective potential of WHO in health development in Europe, Dr Wagner noted that WHO can do certain things that are impossible or inappropriate at the national level, e.g. the drafting of international policies which go beyond the pressure points of special interest groups at the national level. WHO also can promote recommendations which can exert considerable moral pressure. And at yet another level, WHO-sponsored expert committees may be convened to set standards for health programmes. Most importantly, the Regional Office provides a forum for sharing ideas and for airing issues of common concern to the 33 Member States. The Regional Office offers, in effect, opportunities for mutual assistance among its Member States.

Ms I. Kickbusch referred more specifically to the Regional Office's role in health education. After summarizing the three areas of the programme (health promotion, disease prevention, supportive health education), Ms Kickbusch turned to the process of establishing in all three areas a useful dialogue with the many relevant interest groups in the Member States. More easily said than done, she noted. How, for example, can the Regional Office start a dialogue with groups never before spoken with, many of whom are not part of highly visible organizations or even networks? How can the Regional Office establish communication with those groups who are justifiably cautious (even suspicious) of the motives of professional and/or international health bodies? One purpose of the Consultation, she recalled, was to stimulate the process and to suggest how it might continue.

A second element common to all three areas of the Regional Office's health education programme is a perspective whereby the people's values, beliefs, choices and skills in health are seen as the base of the health development and health care pyramid. Professional roles are supplementary. A major task is to identify the interface between lay people and health professionals in this regard. The perspective of lay resources in health clearly implies the need for new research, both substantive and methodological. In the latter regard, qualitative methods (grounded in the experience, definitions, and perceptions of lay people) seem most appropriate.

In all three areas of health education, the Regional Office is aware of, and is committed to avoid, several "traps".

(1) Blaming the victim. Care must be taken not to make health a moral issue where the behaviour of individuals is seen as the central (and sometimes exclusive) cause of the problem. ("If you are sick, you have only yourself to blame.") There must be sensitivity to the multifactorial cause of disease which takes account of personal, environmental and social factors. Solutions must reflect this reality and be applied to problems in ways which involve both personal and collective action. We might best drop the term "lifestyle" (too limited to personal behaviour) and use the more ecologically-based term "quality of life" or work with a concept of "life chances".

(2) Creating an idealized "culture of health". With all our good intentions to help people control their own health destinies, we must guard against dumping on people health "responsibilities" in the romantic belief that they like assuming them anyhow. There are power issues involved in shifting the locus of control in health to individuals and families. The women's role in family health, for example, is affected by such a shift (a benefit or a burden?). There is tremendous variation in what risks people prefer to avoid and what level of health care skill they wish to provide for themselves. In health education programmes, be they promotive, preventive or supportive, there must be a built-in respect for individual preferences and the assurance that there is a good array of options and choices. And we are well advised to remember

that life consists of much more than health (only 10% of a study sample in the United Kingdom rated health as a top priority). There is no justification for health education which involves punitive measures to achieve compliance with the "right" health behaviour.

(3) Mixing messages. One ironic result of the recent appreciation of the multiple etiology of disease is the profusion of information sources and information biases. In organizing what appear to be three distinct sectors of the health education programme, the Regional Office is aware of the necessity for a strategy based on a grid with both personal and social dimensions - an ecological grid.

A third element common to all three sectors of the health education programme is a commitment to both vertical and horizontal approaches in promoting communication and cooperation: vertically through the lay and professional health care systems, and horizontally between these systems; vertically through the voluntary structure in a given self-help interest area, and horizontally across self-help groups as a movement.

The Regional Office staff concluded their introduction by noting that the planning and strategy documents for health education presented a general philosophic perspective and means of achieving the objectives, and that "operationalizing" these objectives with firm targets and activities (particularly the involvement of community groups) must be informed by exchanges such as the present Consultation. There is a need also to further clarify key terms of reference, e.g. self-care and self-help, in a way which will be both sensitive to the range of cultural and national interpretations and sufficiently specific to allow generalizations across cultures and national borders. Suggestions for terminology were proposed for consideration by the group.

It was clear that the concerns raised by several participants regarding the general role of the Regional Office as an effective force in health development could only be partially satisfied. For example, one participant raised the question of the conceptual limits of WHO activities in health. How does WHO differentiate between health education and education per se, and between the impact of health policies versus politics in general? Another asked how WHO could work in the interest of health with national governments whose policies involve collaboration with industries implicated in causing health problems. Yet another raised questions about the hazard of the Regional Office's health education programme "medicalizing" spontaneous popular health care by substituting "allopathic" techniques. How inclusive can/should the programme be regarding the contribution of alternative health care strategies?

3. Scope of self-help and health

3.1 Self-help and mutual aid: an international perspective

Professor A. Katz presented an international perspective on self-help - the mutual-aid group. He stressed this distinction as important to clarify the concept of self-help per se as separable from its many social and organizational forms. Self-help as a social strategy for problem solving and community development is an integral part of the political philosophy of many countries. Mozambique and the United Republic of Tanzania are examples of countries where self-help is built into collective action in agriculture, public health (water purification) and producer cooperatives. Such examples of self-help, as pervasive efforts to advance the social welfare, cast doubt on the popular "stage theory" which asserts that mutual-aid groups and similar forms of self-help in health found in the industrialized world are the exclusive consequence of industrialization and are primarily reactions to an overload of high technology and depersonalization of professional health care. It appears that the benefits of self-help as a productive strategy are appreciated across a broad spectrum of social activities.

The growth of the mutual-aid groups in health has been substantial and rather widespread in North America and Europe. It is estimated that there were close to 750 000 such groups in the United States in 1980 (about 14-15 million people involved), growing from an estimated 500 000 (with 5-10 million people) in 1974. Dr D. Robinson reported that there are about 200 mutual-aid groups in the United Kingdom, while observers in Austria, Belgium, the Federal Republic of Germany, the Netherlands (University of Tilburg), Poland and Yugoslavia, among others, report similar increased interest in this form of self-help. And the range of problems represented by these groups includes nearly all the major disease and disability categories. Studies of mutual-aid groups in the USA, for example, show that mutual-aid groups have been formed for each of the 200 most prevalent diseases and disorders.

Such disease/disability groups appear often to be the result of perceived limitations of orthodox medical approaches and/or the recognition of psychosocial implications of chronic disease. The power of these groups in providing mutual support is clear; membership offers

psychological support as well as an opportunity to share both social and technical skills that individuals have found effective in coping with the health problem. Many mutual-aid groups reach beyond immediate service to their members. Professor Katz' research has shown their interest in influencing the larger social, political and professional environments which affect the health problem in question. Such groups perform an "advocacy" function, e.g. securing greater public attention for the disease or disability as a way of increasing funds for research and service. Others see the need for improving the quality and availability of education of health professionals regarding aspects of the given disease or disability. Thus the mutual-aid group should not be ignored for its real and potential role in influencing social policy and practice in health.

Professor Katz further identified epidemiological, clinical and economic advantages of the mutual-aid group which, by promoting social integration (meaningful social contacts) can help in reducing morbidity and mortality. This contribution is a particularly powerful aspect of mutual aid for those who deviate from the health norm in ways which stigmatize or otherwise result in marginal social status for the individual. Health care benefits stem from the quality and continuity of care immediately available in a mutual-aid group. There is little or no social distance among members so that a caring environment can develop and be sustained. Psychosocial and physical aspects of health care are integrated. The experience of living with a problem common to the group creates a pool of technology for coping and rehabilitation. (Many of these techniques later find their way into the training of health professionals.) So impressive is the epidemiological and clinical contribution of the lay group resource with respect to chronic disease and disability that one can well appreciate the importance of redefining the tasks of the health professional around (1) diagnosis and (2) the educational support of "natural" lay groups as mainly responsible for ongoing treatment.

From the economic standpoint, studies in the USA are beginning to develop a picture of lay self-care as highly cost-effective. Examples include haemophilia (cost reduced by 50%) and haemodialysis at home and biofeedback and meditation in the control of asthma and migraine (a 75% reduction in use of the emergency room). The mutual-aid group contributes to cost-efficiency through its "multiplier" effect, as membership revolves and as family skills are enhanced. Further, mutual-aid groups maintain high efficiency in individual terms; members stop participating if and when the group no longer works for them. There are, of course, no fees involved although occasionally very modest dues or contributions are paid to cover mail and telephone charges and costs of renting space for meetings.

For whom is the mutual-aid group most appropriate? Are there key target groups for the future? Clearly, by definition, those groups already formed reflect society's priorities as well as the opportunity for organizing. Although professionals have helped establish some groups, the largest proportion has been initiated by lay people, particularly those groups responding to inadequacies or inequities in professional care (e.g. women's health groups) or to the discovery of a new problem (e.g. "DES groups" for diethylstilboestrol treatment). There remain, however, a substantial number of highly vulnerable populations where self-care education and self-help groups could play a larger role in reducing risks, promoting health, and facilitating treatment and rehabilitation. The education of children, for example, in self-care skills should receive high priority, particularly regarding symptom recognition, treatment of minor illnesses and injuries, and dealing with health professionals in a productive and safe way. Mutual-aid groups formed around adolescent problems, especially concerning the use of addictive drugs, sexuality and venereal disease, need to be encouraged. The adult disabled and the elderly are especially vulnerable in terms of levels of dependency which compound the strictly clinical implications of chronic diseases and disability. Self-care and mutual aid for rural people can be an immediate and effective health care resource, making it possible to use scarce professional resources productively. For the poor, self-care and self-help can focus on collective action vis à vis environmental stress (poor housing, working conditions, etc.).

While an increasing number of health care professionals acknowledge and support self-care and mutual aid, the mainstream of the professions appear unaware or resistant to the active, organized involvement of lay people in their own medical care. Some of the resistance can be attributed to misunderstanding concerning the "limits" of self-care and mutual aid, the fear that these approaches could (or do) go too far and are thus dangerous, or that they are a poor substitute for professional care. Other professional responses suggest an underlying concern that lay self-care and mutual aid undercut the security of the professional establishment, and erode the professional domain, an area of exclusive expertise. We have seen this resistance to the addition of new health professionals as they challenged the established roles of medicine and now we can see the same attitude regarding the perceived challenge of nonprofessionals to the heretofor sacrosanct territory of professionals. Professor Katz was joined by several participants in urging that the Regional Office confront this resistance through, for example, meetings between self-care and mutual-aid activitists and representatives of the health professions. An open dialogue can help to

clear the air of misperceptions as well as to identify areas of concept and practice needing research. Educators in the health professions, particularly medicine and nursing, can be encouraged by the Regional Office to take the nonprofessional health care resource into account and to begin a reorientation of professional care.

The group was aware that some forms of lay health care, particularly the mutual-aid group, may for some be merely an additional resource to professional care and that some participants in mutual aid may remain (or become) overusers of professional resources, i.e. the effect of medicalization (converting social problems and social solutions to medical problems and medical solutions). The extent of this hazard, however, should not be overdrawn, given that mutual-aid groups fill a gap in professional resources or provide a unique benefit in sharing (social support). For the most part, individuals are attracted to mutual aid through their own initiative or through their social contacts. There is little evidence that mutual-aid groups are being used (much less managed) by health professionals as an extension of the strategies of professional care. This is not to say that mutual-aid activities are necessarily discordant with regard to professional values concerning disease and care; they may, indeed often do, deviate from the medical model, but as complementary rather than dissonant activities. Most members of mutual-aid groups focused, say, on a chronic disease still use professional care. So what may appear to be overuse of health care (both key and professional) may in fact be evidence of greater discrimination regarding the best use of a wider range of health resources. Indeed a key purpose of introducing the subject of mutual aid into the curriculum of health profession schools is to further clarify the related roles of lay and professional care.

3.2 The concept of consumer-centred health care

Professor C. von Ferber presented an overview of the concept of consumer-oriented care in the context of health care in general. He noted that health care as commonly defined in social policy refers only to input of professional health resources and activities.

This definition virtually ignores the actual counter-productivity of professional health care activities. Examples of the latter abound in evidence of iatrogenic disease, consumer dependency, lack of communication between professional and client resulting in the client rejecting (or ignoring or not obtaining) advice, unclear differentiation of professional versus client responsibilities, and the explicit and implicit encouragement of a false sense of security in the client.

Recently we also have become more aware of the inability of professional health care to do very much about promoting health. We now have evidence that environmental factors (both social and physical) are complicit in diseases of our industrial societies. Some solutions, therefore, lie outside the technical fields of medical care. Indeed, we are developing a picture of risks to health as "stressors of the social environment", including life events, role ambiguity, role conflict, status inconsistency, and strain related to the working environment. These factors of disease causation do not easily fit into strategies of intervention based on the present medical model, nor should they. Effective control of social factors in risk to health must emanate from the social sector itself.

A move from a professional to a social or lay strategy in health in coping with illness and promoting health will be resisted by those with vested interests in the status quo. The concept of health care has long been monopolized by health professionals who are not likely to agree to a reduced jurisdiction. (An alternate scenario here, several consultants noted, would be for health professionals to redefine social factors as medical factors and thus control new areas of "health" behaviour.)

Social policies continue to emphasize the development of professional health resources with no corresponding activities to advance the competence of the lay person. The gap between the professional and lay resources appears to be widening. At the same time there are growing contradictions and paradoxes in the rhetoric of health. For example, some aspects of the consumer movement in health demand greater access to professional services and an improvement in their quality. At the same time another perspective on consumerism seeks more self-reliance, and increased lay competence in areas of health care heretofor within the domain of professionals.

There is a need to clarify the currents and cross-currents in the development of policy which could ultimately bring professional and lay resources in health care into a better balance. A starting place would be to recognize the social etiology of many diseases in industrialized Europe. This means raising the public consciousness regarding social causation and acknowledging the competence of members of the public to define their immediate situations. Professional advice may be helpful in this, but it cannot substitute for the input of lay people in defining the

problem from their own standpoint. Secondly, there must be a clear understanding that health activities (as contrasted to medical) are the domain of lay people. The old question of "what are the needs of the clients and how can political intervention mobilize comprehensive professional help to satisfy these needs?" must be replaced by "which problems can be solved only by the clients and how can policy help to supply the appropriate resources to strengthen their competence?"

We are only at the beginning of obtaining a full response to this new question. Even our methods of getting answers will, several participants noted, have to be revised to reflect lay people's construction of reality. Professor von Ferber offered some examples of lay health competence which needs to be strengthened. These include skills in seeking and evaluating epidemiological information on environmental stressors and in organizing for community action. It is clear that lay health action will usually mean social action. This is in contrast to the tradition of professional intervention and professionally dominated health education which focus almost exclusively on individual behaviour change without regard to social precursors ("silent" social control factors).

Professor von Ferber's contribution set the stage for a wide-angle view of the full range of nonprofessional health care resources in the community not by any means limited to self-care and mutual-aid groups. He argued for a broad definition of the social resource in health, urging that we should not limit our perspectives to those resources whose primary, acknowledged purpose is health. Trade unions and the church are examples of important health care resources that should be considered along with organized lay health activities.

3.3 Participation in health care: the Giugliano action research project in Naples

An example of a community-based social action programme in health was presented by Dr S. Panico. It is illustrative of an application of points Professor von Ferber made on using the full social resource in health, redressing the balance between professional and lay resources, involving professionals as enabling resources for lay action, and applying the principle of lay control over problem-posing as well as problem-solving. The Giugliano project carries special significance in that it is a pilot demonstration for major reform in Italy's national health system. Further, its impact could extend beyond Italy, given that the project is part of a coordinated international research effort also involving Algeria, France, and Tunisia.

The Giugliano project is sponsored and operated by the Centre of Social Medicine in a suburban area of Naples. The Centre itself was started in 1975, in response to a severe lack of health services available to a poverty population. A second pressure for establishing the Centre came from the people of Naples, after a serious outbreak of cholera in 1973. It provides health care to 150 000 people.

The Giugliano project represents a "horizontal" model of social development, as contrasted to the orthodox model of "vertical" social assistance. In the "vertical" model the state identifies populations in need, organizes procedures and provides one-by-one specific services. This strategy, Dr Panico noted, has failed to develop a comprehensive understanding of the social contradictions which influence health. It also tends to passify public expectations by offering a service and ignoring the latent opportunities for mobilizing social action toward more global change affecting the community. The horizontal model, on the other hand, is based on the local community and its population, services, culture and forms of poverty, and its power for making social and local policy. The horizontal model enhances local autonomy and encourages the transformation of the notion of single-factor disease causation into a multifactorial concept, whereby a health problem is viewed in its social context. The project method helps the community identify non-fragmented objectives and socially integrating forms of intervention.

A local health project always involves participation of the local people. Participation includes four local groups of problem "interpreters":

- individual users or associations of users of health and welfare services;
- health, social and cultural workers;
- associated structures (e.g. political parties, unions);
- administrative and public functionaries.

Those groups plan and implement the project. The health professionals contribute, but they cannot dominate. Thus what may start out as an isolated health problem involving one individual can, with the input of the four participant groups, open the way for reinterpretation of the problem and

widen the perspective on the underlying social conditions. The key to this process is the technical team and its ability to hear the non-expressed or mis-expressed needs of the community, to know its grid of social contacts, to critically analyse the community's demands, and to identify any harmful features of approaches suggested by health professionals. A crucial figure in this process is the community operator whose task it is to help the community express their real needs, aggregate people according to a common demand, and help form an action group. The community operator is, in effect, a "bargainer" with the community, a grass-roots community organizer.

Evaluation is seen as a tool for permanent correction of the action with respect to the defined objective. Two levels of evaluation may be defined, the first relating to identification of homogeneous groups requiring a project, and the second to the activity of these groups in achieving the objectives. The evaluation questions at each level include the following.

Identification of homogeneous groups

- What was done to create settings for expression of needs? To whom? Where? Have they expressed real needs?
- What "harmful" components have been found in the demands? What prejudices were found in the answers to these demands?
- How many people have been involved in the project? How has the project diffused through the community?
- Have initiatives been achieved? How? Has the project group any form of control/participation in developing the initiatives and achieving the objective?

Activity of homogeneous groups

- How much has the activity of homogeneous groups been extended? Has there been a diffusion of the aims and objectives of the base-derived project?
- Has the homogeneous group kept itself aggregated and found new objectives, if the presence of the community operators has not been continued?
- Has there been any effect of multiplication of initiatives and enlargement of the groups?

Dr Panico emphasized that in terms of project methodology, a self-help group can be seen as a form of participation only if it acts as a "homogeneous" group, with horizontal, base-derived planning.

With regard to the concept of successful participation, for the Giugliano project there must be evidence of the ability and willingness to analyse health problems critically and, when appropriate, to change the way services are usually offered.

Dr Panico's presentation gave clear emphasis to the role of self-help groups in social change, i.e. social activism. In this regard, the importance of the community operator was noted as crucial in helping the group critically analyse their common problem and the solutions offered to them. Without this help, Dr Panico felt that the group would tend to follow old patterns of solution.

In the model presented, the goal is to activate the social component in narrowly defined health problems. One participant raised the possibility that the strategy may work the other way around as well, i.e. activate the health component in narrowly defined social problems.

Evaluation of the Giugliano project relies heavily on qualitative measures, e.g. "Did we generate expression of real needs?" The strategy of qualitative research is difficult in that it relies on sensitive observations, continuous recording and data analysis. Participants noted that qualitative methods in social research as applied to health have been largely neglected in favour of quantitative methods. It is now time to explore wider use of qualitative methods, particularly as they would apply to health programmes which are "grounded" in community initiatives and where lay definitions of health behaviour are sought. Qualitative methods generally can help improve the validity of research on nonprofessional health activities.

3.4 Role of self-help for health education: role of health education for self-help

A central theme which emerged in the Consultation was the interface between the professional worlds of health and education and the lay world of self-care and self-help. Several times

participants pointed out the complexity and delicacy of this relationship, with the implicit assumption that some form of relationship (effective communication) would be necessary in the public interest. Professor Katz, for example, while emphasizing the importance of independent and lay initiated growth of the mutual-aid group, noted the benefits of professional referrals of patients and the availability of professional expertise, should this be sought by the group. In the community development model of the Giugliano project, the relationship of the technical team and community operator in formulating the group and helping to mobilize their action is crucial. Yet even in that case, Dr Panico noted that the goal was to facilitate group action, not to direct or dominate it.

Another approach to maximizing professional contributions to lay initiated self-care and self-help activities, while minimizing professional domination, was described by Dr H. Adriaanse. The State University of Limburg has established a "health shop", an organization of volunteer medical students and students from the social health programme as well as health workers in the neighbourhood in which the health shop is located. The purpose of the health shop is clearly to provide a ready pool of expert health and educational information and advice to individuals and community groups in self-care and self-help. But the health shop also serves as an important link between the professional schools and their communities where information about interests, needs and concerns can flow in both directions. A second "research shop" is planned to facilitate studies of health and health education of interest to both the community and the University.

The organizers of the health shop and research shop realize that the educational process itself is an exciting area for reserch and innovation for both the University and community self-help enterprises. Educational innovations in the preparation of health professionals are presumed to have relevance to community groups as well. Information about these innovations is made available through the health shop. Dr Adriaanse described several educational models that the community should be aware of as useful in various settings, e.g. mutual-aid groups, schools. These strategies are used in health education practice and have obvious relevance for community self-help groups. Four educational models were mentioned.

(1) Confluent education. This notion was pioneered in the USA. It calls for a teaching-learning strategy in which two streams, the affective stream and the cognitive stream, are assumed to be interlinked. The method emphasizes that in teaching, one should always stress both the affective and cognitive sides of a subject.

(2) User-based curriculum development by networking. This educational approach was developed in France. The learners in the system set the framework for the materials (course guides) that they will use. These materials, in turn, are shared by other schools. The central ingredient in this method is more student control over learning and emphasis on experiential learning (e.g. learning arithmetic while working in a store).

(3) Problem-posing education. This method was developed in Brasil on the basis of experience with teaching poor and powerless people how to raise their critical consciousness and to pose problems (in contrast to problem-solving skills). The underlying belief is that "He who defines the problem controls the range of solutions". The approach is community based. Key themes are developed out of the teacher's participant observation and worked through in small groups. The method recalls the work of the "community operator" in the Giugliano project.

(4) A problem-based approach. This method, developed at the University of Limburg, calls for a small group format in which students work on problems taken from practice and set their own activity agendas. Faculty members of relevant disciplines act as consultants to the group. The approach is relevant to the process of technical assistance to self-help groups. Key features are that it is self-directed and uses consultants in a non-dependency producing way.

The health shop stimulates the formation of self-help groups through advertising, e.g. "If you have problem X and would like to talk/meet others with the same problem, please contact us and we will put you in touch with them". Even people with "rare" diseases have been helped to locate others, a service not usually available from the personal physician. To some extent, it was reported, this referral role is carried out by voluntary associations, but the active role of the health shop in family self-help groups in a variety of problem areas is an innovation.

The Netherlands programme represents an effort to reduce the social and conceptual differences between health professionals and their training institutions and the community they serve. The curriculum plan for physicians, nurses and health educators allows maximum exposure to the social complexities of health problems and stresses the relevant (indeed essential) role of lay people in health care. It should make better "listeners" of health professionals and improve their willingness and ability to work with individual patients and community-based self-help groups. At

the same time, the health shop serves the community as an example of non-disabling technical assistance; in effect it provides a new role model of (and for) the helping professions. Several participants, however, pointed out that local physicians who refer patients to resources like the health shop may find their patients becoming less passive, and showing more initiative. Under these circumstances, will they still be willing to refer patients? There is a reasonable basis for concern on this point. Certainly, creating understanding of the role of self-care/self-help (and the health benefits of assertive, competent patients) is important for health care professionals. Those already in practice need special attention in this regard, through postgraduate education, seminars, etc. The Regional Office should give emphasis to this aspect in programmes aimed at encouraging greater use of the lay self-help resource.

3.5 Education for self-care: a general practitioner's view

A closer examination of the relationship of self-care/self-help to the role of the health care professional was provided by Dr B. Henricson, a general practitioner from Sweden. Since 1975, Dr Henricson has had an active interest in self-care. In the context of general practice, there is first of all an attitude toward self-care which must permeate. This attitude reflects the belief that the patient's own contribution to medical care is both a legitimate and essential factor in the care and its outcome. A patient who understands how his/her body functions, who can identify deviance (and its causes) from the normal state, who can interpret symptoms and begin to take effective action, and who knows when and how to use professional care will reap important personal and social benefits in health. To this end, it is a responsibility of the physician to build into his practice an educational plan which exploits every opportunity to teach patients the essentials of health promotion, risk reduction, and a variety of primary methods for self-care in illness. To make this work, the physician must establish a humane relationship with patients - in the form of an egalitarian partnership of mutal respect. Social distance between physician and patient reduces the chances for effective self-care education.

Physicians see themselves as providing a one-on-one service which means they have limited capacity for taking advantage of several educational options; namely, working with groups of patients with similar interest and even moving toward offering self-care education to non-patients, people with interests in general topics of health and health care.

Dr Henricson recounted how his approach to self-care education expanded in and beyond his own practice. His positive experience with self-care education in practice (less revisits) encouraged him to sponsor public lectures on "how to take care of yourself". Lectures on a wide variety of subjects in the local evening school were begun in 1977 - events which were announced in local newspapers and supermarkets. Simple language was used with supplementary films, etc. Attendance grew (on average, 90 people per lecture). Then followed visits to small villages in the area where attendance at self-care sessions was nearly 100%. The results were positive, as indicated in a 16% drop in visits to the central clinic.

Dr Henricson pointed out the scepticism of many physicians regarding self-care education of patients. For example, some voiced concern for the creation of hysterical or hypochondriacal reactions. This, of course, may hide the physician's fear of being bothered by questions, having to explain options and work in a partnership way with the patient. There is little in the training of physicians which would prepare them for their educational role with patients. People (prospective patients), on the other hand, have relatively little knowledge of health and health care and do not have ordinary and easy access to health information in libraries - at least, not sufficient to empower them in primary health care skills. But given the chance, many interested lay people, with assistance from suitable guides on self-care/self-help, in conjunction with courses led by health professionals, can be trained as study leaders. This results in a substantial multiplier effect for extension of self-care education not dependent on physician leadership.

An outstanding problem, Dr Henricson emphasized, is the isolation he and other physicians with interest in doing something about self-care feel. There is no national policy or administrative support for their role in the national health service. Until this situation changes, self-care as promoted by physicians will be limited by their own resources and the occasional opportunity to do a radio or television show. The Regional Office's recognition of the physician's potential role in self-care education, and its high priority, could help to boost enormously the morale of those physicians now engaged in self-care, encourage others to get involved, and stimulate public demand for this educational service. All of this might lead to the direction of funds to support the activity and perhaps even influence medical education to be more aware of this important function in the concept of health care.

3.6 Self-help in the USSR

With the presentation of Professor D.N. Loransky, the group returned to several themes raised earlier, including (1) the role of health education as a diverse strategy which must pay attention to the key role of individual behaviour in prevention and self-care and at the same time recognize structural factors (e.g. stress in the workplace); and (2) the importance of developing exact terminology and terms of reference for health education, self-care, and self-help that are understandable and acceptable to all Member States.

The emphasis on self-help and health education generally in the USSR developed several years ago in response to empirical evidence of the need - and possibilities - for prevention of the complications of surgery by reducing delay in seeking care. A system of health information was begun in one city and extended to others as success was shown in the reduction of post-operative complications and the shortening of the length of hospital stay. This programme was helpful to surgeons in their work, positively influenced patient health care outcomes, and was a substantial financial help to the health care system. The implicit lesson here was that health education programmes, with measurable benefits to patient, health professional and system, gain universal acceptability and support.

Professor Loransky stressed the importance of the authenticity of health education information. It is not a question of disinterest of members of the public in health information or their reluctance to use it, but a matter of assuring that the information provided is scientifically sound and agreed to by scientists. The public must have some assurance that the information or advice is sound and represents an informed consensus. This point recalls a concern raised earlier, namely that the public is often subject to "mixed messages" regarding health risks and preventive practices. The solution may lie in adopting a more rigorous approach to policy on scientific reporting, or centralizing the health education programme, or increasing the sophistication of the public to assess and reconcile evidence as they perceive its relevance to them, or all three.

Random exhortation of the public to follow certain health practices is not effective. In the USSR there is a state health care system and a state system of health education. The latter is a combination of organizations which, together with legal and scientific measures, define and develop health education strategy. The USSR takes seriously the points in the WHO European regional strategy regarding the role of lifestyle in health. This commitment is reflected in the fact that health education is a compulsory function of all personnel in the health care system. Physicians, for example, provide four million hours of patient health education per month, in addition to several additional millions of hours provided by other health workers. The cost is high (in terms of percentage of salaries), but the benefits in health and savings make the approach worthwhile.

The USSR defines self-help in both a narrow and a broad sense. In the narrow sense, the term self-help refers to first aid in acute, critical conditions. Health volunteers are trained to assist medical staff with first-aid education, using various methods as appropriate to the age and learning preferences of the populations. Included here are schoolchildren as well as adults. It was found from surveys that the educational media most preferred were films. A great deal of money is invested in special films, particularly on the subject of first aid. In addition, there is a monthly magazine ("Health") which has a circulation of 12 million. Other magazines are used to reach housewives, and these are booklets devoted to special subjects.

In the broad sense, self-help refers to the preservation, strengthening and rehabilitation of one's health. There is special concern for health problems of higher prevalence, e.g. cardiovascular diseases, digestive disorders, traffic accidents and childhood accidents. The self-help education goals with regard to major chronic diseases like cardiovascular disease and cancer are (1) promotion of rehabilitation skills and (2) prevention of relapses.

Self-help in this broad definition is part of many programmes designed for children (1-10 form), parents and the general public. One hundred ministries are involved actively in this aspect of self-help education. Each programme is approved by the ministries of health and education. Now there is increased attention to the needs of healthy people. This includes recommendations regarding work and everyday life. This new emphasis, however, is not to the detriment of the needs of the chronically ill, particularly with regard to developing self-care skills for home care, e.g. urine testing for diabetes.

Dr Loransky concluded by stressing the importance of self-help. In principle, he noted, the members of the group were speaking of the same range of issues and approaches. However, it is important to develop a common understanding of the terminology used, and a more exact definition of what is referred to. The Regional Office could provide a useful service in this regard.

Participants inquired about the existence of self-help groups in the USSR - groups of people with similar health problems who meet together for support and sharing of ideas on coping with their common problem. It is recommended that such groups should be created within the medical establishment. These groups are formed within the context of "schools of health", but they are not for every disease. Groups are not formed outside the system, as it is believed that they should have access to expert medical advice. On the other hand, there are citizen groups formed around hospitals. They can recommend programmes of special interest to the community served by the hospital.

There was also an inquiry about how psychosocial aspects of chronic disease are attended to. Dr Loransky responded by noting the existence of more than 50 institutes, in addition to the Central Institute for Scientific Research in Health Education, undertaking research on this aspect. The aim is to elaborate carefully the relationship of social/psychological factors to health.

3.7 The Feminist Women's Health Centre in Berlin (West)

In recent years the self-help and self-care developments have received a major stimulus from the women's health movement. As part of the overall movement to attain equal rights for women, the growth of feminist women's health centres has focused on the inadequacies and abuses in health care to which women are subjected. The first such centre, established in Los Angeles, was a prototype which spread throughout the USA and, with variations appropriate to a given culture and society, centres were organized in Europe as well. Ms J. Murphy and Ms B. Marewski described the organization, goals and programmes of the Feminist Women's Health Centre in Berlin (West) and presented a list of demands related to the functioning of the Centre and women's health generally.

Fifteen women work at the Centre. Of these, only two or three receive pay. Funding comes from a variety of sources including donations, fees from courses and counselling, the sale of a journal, and the Office of Employment (job training programme).

There are three main activities of the Centre: self-help courses, counselling groups and public relations. Self-help courses are offered both at the Centre and in the context of adult education programmes. These are available free or at a minimum fee. Emphasis is on strengthening the self-care competence of women, starting with learning about the female body - its structure, functions and special risks. Alternative healing methods, including natural methods, e.g. biofeedback and meditation, are taught. Group methods of discussion are used predominantly, with each course lasting about six weeks. Participants in these courses are encouraged to start their own groups.

Counselling groups are formed around interests in birth control and gynaecology. The Centre now provides a diaphragm fitting service to supplement the regular medical resources. The diaphragm is not popular among physicians in the country, most of whom have never learned to fit them. This is a serious deficiency in medical education, and one which the Centre would like to see corrected. It is one function of the Centre which the women would like to see taken over by physicians.

Public relations has as its goal the widest possible distribution of information on women's health, health rights, and demands for reform. The Centre has organized an archive of materials, distributes a journal on women's health, and undertakes to sponsor broadcasts, newspaper articles, public lectures and conferences. It is important that as many women as possible be reached beyond the internal services at the Centre.

Ms Murphy and Ms Marewski presented 11 demands which form a powerful political agenda for the improvement of women's health. They are in summary:

(1) public funding to organize training programmes for health workers in women's health centres;

(2) public funding for continuing education within the women's health movement and for the exchange of ideas and information among the various centres;

(3) assistance for women's research projects and surveys oriented to women's needs, whereby women would determine the content, methodology and research personnel;

(4) official recognition for women's self-help centres as sanctioned training centres in women's health (as trainers of trainers);

(5) official recognition of the role of centre health workers as a new professional role, with special skills and integrity;

(6) protection from medical methods which are hazardous to women's health (e.g. medication, abortion methods);

(7) performance by physicians of diaphragm fitting services and other activities the Centre does by default of the medical system;

(8) ending of experimentation on women's bodies;

(9) ending of forced sterilization and clitoridectomies;

(10) recognition by practitioners of natural healing methods;

(11) development of a health system which does not promote and profit from sickness.

It was clear from the group's comments and discussion that the women's health movement in Europe has been "doing battle" virtually alone, with little support from official authorities or the established health professions. Indeed, there have been multiple sources and kinds of resistance. While women's groups have accepted these challenges, they are now seeking collaboration and support within the network of women's groups and from other self-help and self-care interest groups. In this latter respect it is necessary to take a cautious attitude toward some proposals like establishing a "clearing-house" as an umbrella service to all self-help/self-care activities, including those of women's health groups. Such a general plan could result in the women's groups losing control of an important development tool. Further, a general clearing-house on self-help may be at least redundant and at most erosive of an already established women's self-help network. The group noted that the women's health movement highlights the political dimension of self-help and the importance of women maintaining the integrity of their political focus and unique concerns. Women's groups must define their own problems, their own priorities, and their own identity. The women's movement in health has the clear opportunity to effect wider social transformations that influence the health of all people. This energy should be nurtured, not captured.

The Regional Office can and should examine the demands of the Centre and other women's groups and respond where its charter and resources permit. Clearly a starting point is to recognize these organizations as important, legitimate, and effective contributors to health care. This recognition can take the form of women's groups being represented in consultations, as in the present case, or being invited to serve on expert advisory panels, and to co-sponsor with WHO conferences on health topics of concern to women.

3.8 Research issues in self-care: role of the family with special regard to chronic illness

With a presentation on research issues in self-care by Dr A. Ostrowska, the participants began to look at self-care/self-help ideologies *per se*. Previous materials showed the wide and varied social and health benefits of these concepts as well as many barriers - technical, professional, and political - associated with their full application. But it was also considered an obligation of the Consultation to explore aspects of the possible limitations, visible or latent, in the promulgation of self-care/self-help. That meant adopting a social perspective which would reveal something about the status of those social institutions most likely to use or be affected by programmes stressing self-care/self-help. Central among such institutions is the family. Dr Ostrowska said her purpose was to examine changes in the family's social context from the standpoint of its viability as an appropriate source of self-care/self-help, and to suggest policy changes which might support the family's role with regard to its self-care/self-help functions. She had chosen the matter of chronic illness (broadly defined to include a panoply of conditions requiring an individual to have permanent help from others) because of the general prevalence of such conditions and because of their vast implications for self-care/self-help.

The social context of the family may be a more important determinant of the level of self-care, care-giving and the use of mutual aid, than internal factors such as roles, activities and expectations of family members regarding the care of a dependent member. In any case, analysing the reality and potential of the family in caring for a dependent member will have to account for the full range of variables - from personal features of the family (e.g. educational levels, social status, lifestyle) to external factors such as the availability of medical services and macrosocial variables including the position of the family in a social network. It is also necessary to account for cultural and historical variations which may influence the family's

possible participation in self-care and care-giving and use of external support groups (mutual aid). In addition, it should be remembered that families are living entities whose ability to cope and give care change over time.

Research on the relative impact of these and other variables is sparse, although some variables (like higher levels of the family's medical knowledge) have been shown to be associated with the likelihood of a family assuming a comprehensive caring role.

Dr Ostrowska noted the historical changes in family relationships and values regarding care of its members, with families today less able to take care of their disabled, long-term dependent members. External medical institutions have provided this care, but with little satisfaction of either patient, family, or the medical institutions which are not so interested in the non-clinical aspects of chronic disease care. Recent rises in medical costs and the revelation of iatrogenic effects of institutional care have caused a resurgence of interest in family care. There is also the possibility that the new attractiveness of home care may be influenced by motives that suggest a kind of socioeconomic manipulation, e.g. keeping women busy at home as care-givers in a period of rising unemployment. There is definitely a need for research to justify the call to increase home self-care/self-help.

At this stage, we are in a rather tenuous position regarding specific policies on the family as a resource in health care for the chronically ill. Both situational factors and motivational factors (e.g. willingness to assure caring role) need further study, particularly the latter. These factors are themselves changing with new forms of family structure. In addition, research on family self-care must be precise regarding the potential for specific functions, e.g. symptoms recognition, technical help, negotiating with external professional services, etc. Research also must focus on the potential negative impact of increased self-care on family care-givers, particularly women who are most vulnerable to the additional burdens of caring. Finally, studies should identify those health conditions in which self-care is particularly cost-beneficial and required.

In any case, Dr Ostrowska stressed, increasing family self-care on behalf of a dependent member should be accompanied by the development of external support agencies working not to replace family health care functions but rather to collaborate with them. At the same time, general policies emphasizing the strengthening of self-care by families must be sensitive to existing inequities of access to health care as a whole. Will family self-care policies help to abolish or only diminish these inequalities?

Consultants appeared to agree with the research agenda outlined by Dr Ostrowska, particularly on the matter of policies which may place an increased burden on women as care-givers.

Several consultants noted that separation of caring and curing functions represents a false dichotomy. Caring is a constant dimension of curing. (This indeed is the basic rationale in the development of mutual-aid groups.) In calculating whether or not a family can cope with a particular health problem, its affective caring potential must be accounted for. Actually, the assessment strategy should start with the caring dimension as the key factor. Mutual-aid group members experience growth in this respect and it is probably true that families confronted with care for a dependent member will similarly undergo growth in their caring capability. Families are not static.

Mutual-aid groups can help reduce the psychological and practical workload on families and especially on women and the poor. However, present social policies often deny self-care/self-help resources in those who could benefit most. The restriction of these options results in increased dependency of the family and in more rigid fixing of care-giving roles in the family.

Members of the group stressed the many "myths" about family which tend to thwart or distort health policies which would involve the family in health care in an appropriate and protective way. Families are enormously flexible institutions, and while they are smaller than they were a few generations ago, new sharing modalities are commonly developing between families. We must pay a lot more attention to friendship networks and other elements of the local, nonprofessional, non-official, health care delivery system. These may, in effect, be compensatory for changes in family structure. And with regard to the actual productivity of the family itself in health care, we should consider the impact of wider economic considerations.

3.9 Key role of personal and local self-help in a new development path

Mr J. Robertson presented a compelling agreement for a strategy of self-help development in health within the larger frame of economic, political and social change facing the industrialized

world. This will only be fully effective, however, (1) if self-help in health care becomes a part of a more general ethos of self-help, including taking a more active role in shaping the environment, and (2) if self-help by individuals reinforces and is reinforced by attitudes and practices of mutal aid and community self-help among other people in the same locality. For this purpose personal self-help techniques must be linked with community self-help techniques, and professionals concerned with the future of health must work closely with professionals concerned with the future of other aspects of personal, family, social and economic life.

The above thesis is relevant to an analysis of a scenario of social change toward a post-industrial society. This scenario holds that the focal point of growth in the future will be the development of people in harmony with the ecosystem. It implies a shift from quantitative growth toward emphasis on improving the quality of life. It implies a new development path in which nurturing, self-help, self-reliance, mutual aid and decentralization would be key aspects. Health and fulfilment of the human potential would be among its explicit goals. Health for all by the year 2000 is dependent on this scenario of change.

Some specific implications of this change were outlined by Mr Robertson.

(1) Increases in "personal" work - on small farms, in small firms, in small community enterprises, and in the home and neighbourhood. There will be more part-time work, a fairer distribution of paid and unpaid work between men and women. Good work for all will replace the present goal of full employment.

(2) Industry will shift emphasis toward recycling, economizing, manufacturing more durable goods, and promoting small-scale technologies and do-it-yourself activities.

(3) Industrial societies will become far more self-sufficient in food, with more small farms, more home gardens.

(4) People will live nearer their work, with more farming in cities and more manufacturing in the country. More people will provide more direct service to each other. More people will spend more time at home working and living together.

(5) Education, health and welfare functions will be increasingly self-delivered among people with less of a role for professional organizations.

(6) Generally, there will be a shift toward greater autonomy and self-sufficiency at local and regional levels - particularly as concerns food and energy.

This scenario may cause some consternation among health professionals who argue the issue of the most important determinants of health and what/who is responsible - society or the individual. The dilemma is a false one, given that both determinants are complicit and both must participate in improving health. Of particular importance is the approach that enables people to help themselves and by so doing also to participate in changing their environment. A central concept, then, for the new development path will be self-development for persons and communities, and the link between the two. Evidence of this already happening was described by Mr Robertson, both from the standpoint of personal empowerment (e.g. self-care) and community health (e.g. self-help community work groups). What may be required now is a method to help a local community inventory its needs and its human potential for development as a way of mobilizing energy and planning for community action. To be effective contributors to this process, health professionals must become involved with community development from a wider perspective, concerning themselves with other aspects of life which define health. This does not mean that health professionals and other professionals should abandon their special expertise; on the contrary, it means that they must integrate their contributions in a wider framework while continuing to offer their special services where indicated. The notion of where indicated, however, must be a realistic reflection of the limits of positive professional benefit. This is particularly important for the remedial professions which, at least in their traditional roles, cannot create conditions which positively foster wellbeing. Their linkage role in the new development path must lie in helping people create those conditions for themselves.

What practical ways are there for health professionals to contribute most effectively to the creation of a healthier society enabling people to achieve healthier lives and a healthier physical, social and economic environment? Mr Robertson gave six suggestions.

(1) Become involved in discussions of the future of industrialized society.

(2) Invite other professional and managerial groups and organizations to discuss the implications for society in the year 2000 of different scenarios for the development of health care (e.g. routine use of high technology medical care; government responsibility for all health problems; individual responsibility for personal health and wellbeing).

(3) Invite other professional and managerial groups to discuss the health implications of alternative future developments in work, employment, food and agriculture, the built-up environment, energy, etc.

(4) Invite therapists and counsellors experienced in techniques which enable individuals to practise self-help to have discussions with people experienced in the enabling techniques of self-help and local group action on what practical ways could be opened up for closer links between the two.

(5) Involve people in self-help community action groups.

(6) Cooperatively initiate, with self-help groups and community health centres, projects aimed at enabling people to extend their personal self-help activities to involvement in community action, if they wish to do so (as in the Giugliano project).

These suggestions could be taken up by the Regional Office in its commitment to the regional strategy for attaining health for all by the year 2000.

Consultants sought some clarification regarding the implications of the scenario for the new development path for the poor and the unemployed, and wondered whether this post-industrial era might not be particularly burdensome on the most vulnerable members of society. There was a general feeling that, as in previous massive evolutionary changes in society, there is the likelihood that the change will have its share of negative consequences. It is not, however, easily predictable that the historically vulnerable poor and unemployed will be the victims. Structural shifts in the concept of employment and economic diversification, as described by Mr Robertson, could create different vulnerables, such as those at present employed in service industries that will no longer be required, or indeed certain categories of professionals who are related to high-technology institutions. Serving as a partial buffer to this eventuality is one factor that is not part of the industrial revolution, namely an extraordinary diversity in options for access to the goals, services and opportunities. In theory at least, equity in achieving a better quality of life (and health) for all seems a reasonable expectation - and the prospects are certainly more hopeful than those offered by present variations in the industrial system.

4. Feasibility of a European clearing-house on self-help and health

Mr S. Hatch was commissioned by the Regional Office to explore the feasibility of establishing some form of clearing-house on self-help as a collaborating centre at a site to be determined. This was the first step in the Regional Office's process of applying a style of informed decision making. Mr Hatch presented preliminary information obtained from fact-finding visits to selected self-help research projects in Europe, in the form of an interim report to the group. He will then revise the report in the light of the group's input and recommendations, and submit a final version by early 1981. This final report will include additional background information on organized self-help in the countries under discussion and will consider how a European clearing-house might relate to local support systems for self-help.

Mr Hatch prefaced his interim report by stating the view of a number of people that self-help is a rather fragile phenomenon under threat from a variety of interests that want to take it over. However and whoever such perceived threats might be, it is important to seriously bear this concern in mind, as well as the caveat "do not harm", in the discussions of support for self-help groups. One response to this could be to adopt a "hands off self-help" policy. But the realities of the present relationship of professionals to self-help groups, and the interest many groups have in recognition and cooperation of professionals, suggest a more useful policy. This would be to strengthen the capacity of self-help groups to establish the kind of relationship they want with professionals and other outsiders and to develop greater sensitivity toward, and understanding of, self-help among those likely to come in contact with self-help groups.

A first step in deciding what would be an appropriate support structure for self-help is to find out what their needs are. Four categories of need were proposed:

(1) collecting and disseminating information;

(2) providing resources and facilities;

(3) supporting individual groups;

(4) developing policy and practice in the wider health system.

Taking into consideration the concern about interventionism and the practical and technical realities of what a European (non-local) support resource might offer, consideration should be given to the needs of categories (1) and (4). There was consensus among the researchers surveyed that the role of developing policy and practice would be the main justification for European and national clearing-houses. Such clearing-houses could provide an input into national and international policies - an input which would reflect the grass-roots of practice. The clearing-houses could stimulate growth of self-help by disseminating ideas and information and creating a favourable climate of public opinion on the subject. Facilitating evaluative research and disseminating results is another potential contribution. This could help clarify the potential and limitations of organized self-help and encourage the development and acceptance of a wider definition of health care which includes the active involvement of the intended beneficiaries.

There remains to be settled the matter of defining "self-help" in terms of its purpose, i.e. encouraging a more active role on the part of the ordinary citizen in health care and the promotion of health. This would allow the Euroepan clearing-house to be active in the areas of self-care, patient/consumer participation, and the use of volunteers. Reference could also be made to nonprofessional health care resources generally, e.g. unions, religious organizations. The Regional Office should give consideration to the question of a narrow definition of self-help, or the broad one suggested above, in determining the scope of clearing-house activities.

Mr Hatch's report included a summary of his findings on the suitability of various locations for a clearing-house. His criteria were: broad interest in self-help, range of skills and knowledge, research/policy experience, institutional and financial base, and desire to take on the responsiblity. The project on self-help groups in health, based in the Medical Sociology Department of the University of Hamburg, satisfies all criteria with the exception of experience in the application of research to policy and practice. If selected, ways of including such experience in the project should be considered.

The first issue raised by Mr Hatch's report, e.g. how can a clearing-house help without harming, was viewed by several participants as reflecting one of the central concerns of the meeting: namely, the relationship between the lay health movement and health professionals. We need to pay considerably more attention to this key issue and to analyse existing strategies (organized and naturally occurring) of cooperation. What, for instance, are the pathological symptoms of insipient "colonialism", cooptation, and how might professional resources be exploited in a productive and safe manner? Is the more passive relationship model (as in Sweden where experts are called on by self-help groups when needed) as productive in the interests of the self-help group as a more continuous relationship could be? Does the purist strategy of "going it alone" have its own built-in limitations vis-à-vis influencing the wider health care system? What kind of generalist local support system would be most appropriate, e.g. local councils of voluntary agencies as a mediating resource between professionals and self-help groups? How can increased professional referrals be achieved without compromising control of the self-help group's approaches and values? It is precisely questions of this order that a clearing-house might address and perform an active advisory service to its constituents.

There seemed to be consensus on the matter of not being confined to the narrow definition of self-help, but rather developing a wide taxonomy which includes interest in a variety of forms and activities pertaining to nonprofessional initiatives in healt. and health care. This brought the participants back to their continuing concern that the definition of self-help and self-care as general terms of reference for all health education activities of the Regional Office should have both sufficient sensitivity and specificity to encompass relevant activites in all 33 Member States. Again, a central task of the clearing-house could be the design of appropriate information systems which transcend (interpret, correlate, reconcile) cultural and national differences in self-help experience. There is a need to explore variations in both the ethic and practice of self-help.

Suggestions regarding the functions of a clearing-house seemed to imply several categories of possible beneficiaries. These include: the "practitioners" of self-help and self-care, patients, consumers, volunteers; the academics studying lay health initiatives; WHO programme staff; government policy-making bodies and administrators; and health care professionals. Each will require access to information appropriate to its interests and responsibilities. The complexity

and cost of such a service have to be appreciated. Practical limitations of the Regional Office resources argue for a mechanism such as "the collaborating centre" as being viable for seeking additional (outside WHO) funds.

5. Conclusions and recommendations

As should be obvious from reading this report of the Consultation on Self-Help and Health, participants offered suggestions throughout the presentations and discussions. In the main, it was not their style to offer "recommendations" as a terminal exercise where the contexts of the precipitating considerations are lost. To abstract them here is a hazardous undertaking, but for the sake of emphasis several of the conclusions and recommendations are listed.

5.1 An almost casual slippage from one term to another, e.g. self-help, mutual aid, self-care, lay health care, etc., reflects the early stage of growth in society's general awareness of the complexity of nonprofessional health activities and the heretofore virtual neglect of these activities by academics and health planners/administrators. Any organized effort to study or actively support these activities must now have the benefit of a carefully devised taxonomy of terms. This task should be informed by representatives from among those engaged in the relevant activities and from all 33 Member States.

5.2 Self-help activities, broadly and diversely defined, must be expanded to all levels of society in the European Region. This means that there should be a concerted effort to ensure the availability of self-help methods to poor countries and poor people in the more affluent countries.

5.3 Self-help should be encouraged on a multi-level basis with the understanding that health empowerment results in both personal and social action. Health is a social idea. The false dichotomy between personal health behaviour and social factors in health can and should be set aside in planning health development programmes. Health for all by the year 2000 can only be achieved in an integrated perspective. Indeed, at another level, collective efforts in strictly defined health spheres should encourage collaboration with other community development enterprises, e.g. housing, employment, agriculture, energy, economy. Self-help should be appreciated for its more generic contribution to community development.

5.4 Research on the contribution of nonprofessional resources in health, both self-initiated and organized, both individual and collective, needs stimulation and technical assistance. Lay participation in studies of these essentially lay phenomena is essential, and it should be participation through all stages of research from hypothesis to interpretation of findings. In the latter respect, the outcomes observed should be relevant to the perceived goals of lay people involved. Greater emphasis on qualitative social research is recommended.

5.5 There are gaps and biases in our knowledge of indigenous (naturally occurring) self-care undertaken by individuals and family members. Most research has been at the micro level (personal characteristics of individuals or internal characteristics of families). We need to balance (and correlate) this with research at the macro level (the social context of individuals and families including such factors as the relationship of self-care practices, the availability of professional services, and the social connectedness (network status) of individuals/families as a factor influencing self-care practices).

5.6 Efforts should be made to reduce the resistance of health professionals to the role of self-care and self-help, including the introduction of these concepts in professional education.

5.7 Studies/demonstrations should be encouraged on ways and means of making professional contributions to self-care/self-help more effective and at the same time non-cooptative.

5.8 It is important to establish a balanced view of health promotion in Europe which avoids "victim blaming", emphasizes social as well as personal action in health, and views health as a means - not an end - by focusing on "quality of life" rather than "lifestyle".

The meeting focused its attention on the central theme of the Regional Office's role in furthering the ethic and practice of self-help in health. Clearly a start has been made, as reflected in the medium-term programme on health education and in the sponsorship of the meeting. A large number of contacts have been made with people in the self-help/self-care "movement" and they should continue. In effect the Regional Office has sought to become informed of the needs and preferences of those active in self-help and to seek their advice with regard to the WHO role. The question now is whether (and how) the Regional Office should take steps to strengthen the infrastructure of self-help development. Whatever the infrastructure, it must be an integrating one which brings people and ideas into contact while avoiding cooptation. Reflecting on the above

conclusions and recommendations (and others seen in the body of this report), it is obvious that the health education approach must be continuously informed by the constituent nongovernmental interest groups through meetings, workshops, consultation groups and on-the-ground field exposure of the Regional Office staff. Secondly, it is obvious from the range of activities proposed (or needs to be addressed) that the Regional Office will have to seek additional funding external to its limited budget for health education. Some form of collaborating centre(s) is a viable possibility in this respect. Its (or their) functions, however, need to be more fully spelled out. Decisions regarding these functions should take into account what is already available elsewhere (e.g. women's self-help clearing-houses), the expressed concerns about cooptation, and myriad logistical limitations.

Many supporting services at the Regional Office could be made available at a non-interventionist level. Of particular value would be a library resource with the capability of broad bibliographic searches, a substantial collecting system for "soft" materials (unpublished documents), tape and film collections, etc. Additional information services such as a health education (self-help oriented) newsletter would be useful as would periodic bulletins with news of self-help/self-care activities.

At a somewhat more active level, the Regional Office could co-sponsor mini-workshops at the country or even local levels, including workshops on specific needs as well as workshops which would give professionals and self-help groups a neutral ground for dialogue. Locally-based, co-sponsored demonstration projects can be initiated. Grants and fellowships for those working in self-help/self-care situations might be a useful mechanism for facilitating communication and stimulating innovation. And at an even more active level, direct field consultation of the Regional Office health education staff (or their designates) could be considered along the model developed by Dr D. Robinson for WHO headquarters.

The group recognized the authority which resides in the prestige of WHO. It can be a powerful ally in gaining recognition of the legitimate and vital contribution of self-help/self-care and nonprofessional health care resources generally. It can allow WHO to make known its intent to help those resources develop, and its further intent to seek their advice and support in developing programmes, policies and recommendations. WHO-published statements to this effect are welcome, but it is certain that these will be hollow words without action to augment the health education team and supporting resources at the Regional Office and to strengthen its ability to reach out to its nongovernmental constituents at the local level.

Annex

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